



# A Pilot Study on Women's Health Education in Rural Guatemala: Impact on Beliefs and Behaviors

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## **ABSTRACT**

*Background:* Great disparities exist in women's health outcomes in rural indigenous communities in Guatemala. Indigenous women are less likely to utilize family planning and cervical cancer screening services. This pilot study assessed baseline women's health knowledge as well as the effects of a comprehensive women's health course on women's health knowledge and behaviors.

*Methodology:* From February to November 2013, 61 participants in a seven-week language appropriate women's health curriculum were evaluated before and after the course using a 10-item knowledge assessment. Rates of cervical cancer screening and birth control utilization were assessed by self-report before and after the course.

*Results:* Several women's health knowledge deficits were noted: the belief that birth control causes cancer, the inability to name symptoms of sexually transmitted infections, the lack of understanding of pap smears, and the lack of familiarity with condoms. The average pre-test score was 54.6%; this increased to 83.7% on the post-test ( $p < 0.0001$ ). 79% of participants had received a pap smear prior to the course; this percentage increased to 92% by the time of the post-test ( $p = 0.013$ ). 53% of participants had utilized birth control prior to the course; at the time of the post-test the percentage was 54%, which was not statistically significant ( $p = 1$ ).

*Conclusions:* This study reveals important patterns in women's health beliefs in rural Guatemala, which can be used to shape future educational initiatives. It shows that a seven-week women's health curriculum was effective in improving scores on a knowledge assessment, with a modest positive impact on women's health behaviors.

*Key Words:* Guatemala, indigenous health, women's health, health education, cervical cancer, birth control

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## **GLOSSARY**

HIV: human immunodeficiency virus

HPV: human papillomavirus

IUD: intrauterine device

Ladino/a: term used in Guatemala to indicate a person who is not indigenous

NGO: nongovernmental organization

STI: sexually transmitted infection

TFR: total fertility rate

VIA/Cryo: visual inspection with acetic acid and cryotherapy

## INTRODUCTION

### *Guatemala and Indigeneity*

Guatemala is a Mesoamerican nation with a large indigenous Maya population, with approximately 66% of its 14.3 million inhabitants identifying as indigenous (Montenegro & Stephens, 2006). Of all countries in the Americas, Guatemala has the second lowest Human Development Index, making it one of the most impoverished nations in Latin America (United Nations Development Programme, 2013). The indigenous population shoulders the brunt of this poverty: over three-quarters of the indigenous population lives in poverty as compared to 41% of the Ladino (non-indigenous) population (Pan American Health Organization [PAHO], 2012). In rural areas, indigenous workers earn wages that are 34% lower than their Ladino counterparts (PAHO, 2012).

Access to education is also unequal: the nationwide average number of years of schooling is 5.3, whereas among the indigenous population it is only 2.1 years (PAHO, 2012). The overall illiteracy rate in 2010 was 18.5% (19.9% for women); however, rates of illiteracy in rural and indigenous communities are often significantly higher. Language frequently serves as a barrier to services, as over 20 distinct indigenous languages are spoken in Guatemala but the majority of services, particularly health care, are provided in Spanish only (Rohloff, Kraemer Diaz, & Dasgupta, 2011).

Discrimination against indigenous communities also plays into these stark inequalities.

Guatemala is a post-war nation, recovering from a civil war which lasted over 30 years, ending with the signing of the Peace Accords in 1996 (PAHO, 2012). This conflict was marked by mass murders and brutality inflicted upon indigenous communities, which has led to the recent trial of former military ruler Efraín Ríos Montt for genocide and war crimes (“Guatemala Ríos Montt,”

2013). The indigenous population has continued to suffer from institutionalized discrimination, often facing significant cultural and linguistic barriers to government services, as well as mistreatment from Ladino providers of services. This has led to a deep mistrust in government programs, particularly in the health care sector (Rohloff et al., 2011).

Guatemala's complex milieu of socioeconomic inequalities, discrimination, and language barriers have resulted in great disparities in health outcomes between indigenous and Ladino populations (Ministerio de Salud Pública y Asistencia Social [MSPAS] et al., 2009). Disparities in health outcomes in indigenous populations occur worldwide and have been a recent focus in the global health community (King, Smith, & Gracey, 2009; Horton, 2006). As Guatemala has one of the largest indigenous populations in Latin America, these issues are particularly salient (Montenegro & Stephens, 2006). Worldwide, indigenous communities have higher rates of mortality and morbidity, with shortened life expectancies (Montenegro & Stephens, 2006). Indigenous populations often have limited access to health services, and when these services do exist, they are frequently culturally inappropriate (Montenegro & Stephens, 2006). The reasons for these disparities are complex and extend beyond classic socioeconomic inequalities, tying into the "history of colonization, globalization, migration, loss of language and culture, and disconnection from the land" (King et al., 2009). Services and programs are often fragmented, offered by disconnected governmental and non-governmental programs (King et al., 2009).

### *Health Care in Guatemala*

The Guatemalan health sector is a complex system composed of a patchwork of private, public, and nongovernmental organizations (NGOs). In the public sector, the Guatemalan government has invested limited public spending in health care: in 2008, the government invested US\$97 per capita on health care—less than any other Latin American country (Ishida, Stupp, Turcios-Ruiz, William, & Espinoza, 2012). Furthermore, the majority of this health care spending is

concentrated in the capital city, where over 80% of Guatemalan physicians practice (Rohloff, 2012). As a result, health posts in rural indigenous areas are frequently understaffed and under-resourced, leading to spotty provision of services and medications. It is not uncommon for government hospitals to require patients' family members to provide their own food, diapers, and medical supplies, including phlebotomy tubes for blood tests. Indigenous patients often mistrust government health posts due to discrimination, culturally inappropriate care, and the belief that they are not attended well (Rohloff et al., 2011).

The nongovernmental sector in Guatemala is substantial, and is thought to have expanded significantly since the earthquake of 1976. Currently there are estimated to be over 10,000 NGOs in Guatemala, many of which provide health services. These NGOs are largely unregulated by the government, leading to great variation of availability and quality of services depending on the region (Rohloff et al., 2011). Many patients seek care at multiple sites, including both governmental and non-governmental organizations, often receiving conflicting diagnoses and recommendations. This generally leaves patients without a true medical home or primary care physician, which has a substantial impact on routine health maintenance (Rohloff et al., 2011).

### *Reproductive Health in Guatemala*

Women's reproductive health outcomes are a striking example of inequalities in the health care system. Reproductive health data, particularly involving the incidence of sexually transmitted infections (STIs), is limited in Guatemala. The rates of STIs are not well monitored beyond the capital city, and most studies have focused on vulnerable groups such as sex workers rather than the general population (Ministerio de Salud Pública y Asistencia Social, Programa Nacional de Prevención y Control de ITS, VIH, y SIDA, 2008). Some estimates, however, suggest that the prevalence of HIV among indigenous Guatemalans is three times higher than the national rate

(Gracey & King, 2009). Although screening tests for gonorrhea and chlamydia are not commonly available in Guatemala, a recent study surveyed 344 sexually active women and found that 18.9% had recently experienced STI symptoms (Ikeda, Schaffer, Sac Ixcot, Page, & Hearst, 2013). In rural indigenous communities, poor wages and frequent underemployment drive many men to migrate in search of a steady income. This pattern of behavior has been shown to be associated with a more than twofold increase in odds of STI symptoms among female partners of these migrants (Ikeda et al., 2013). Despite this increased risk, members of these communities often lack access to reproductive health education. A survey from 2007 found that of 839 indigenous men and women ages 18-49, 37.4% did not know what a condom is and 47.6% did not know what an STI is (Ikeda et al., 2013). The lack of screening exams for STIs and limited reproductive health education, combined with frequent migration, creates a perfect storm for rising rates of STIs in rural indigenous communities.

Cervical cancer—now definitively linked to the human papillomavirus, an STI (Scarinci et al., 2010)—is the second most common cancer affecting women in Guatemala, with the third highest mortality rate (GLOBOCAN, 2012). Cancers of reproductive origin made up approximately 40% of diagnoses of female cancer patients presenting to the national cancer hospital in Guatemala in 2012 (Registro Hospitalario, 2013). This can be contrasted with the United States, where cervical cancer mortality rates have fallen to the tenth highest (GLOBOCAN, 2012). This is due to significant efforts to implement regular pap smears to screen for HPV and cervical dysplasia. In Guatemala, although pap smears are offered at government health centers, these services are often inconsistent due to lack of funding and materials. Women frequently report that they never receive a copy of their pap smear results, despite having had a pap smear. This leads to frustration for patients, as well as concerns that cases of cervical dysplasia are being overlooked due to poor patient follow-up. Embarrassment and lack of understanding of the



purpose of pap smears also contribute to low cervical cancer screening rates, particularly among women in rural indigenous communities. According to the National Maternal and Infant Health Survey done in 2010, 78% of Mayan women aged 15-49 reported never having had a pelvic exam (Ikeda et al., 2013). A recent study also found that in Guatemala a large gradient exists between wealth and the probability of recent cervical cancer screening, and that the probability of screening among ladino women was 80% higher than among indigenous women (Soneji & Fukui, 2013).

Although regular HPV screening is not available, a study from 2009 found that of 297 sex workers and 297 women from the general population, cervical HPV DNA prevalence was 67.3% and 38.1% respectively (Valles et al., 2009). Although this study focused on largely Ladino communities—there is a paucity of STI prevalence data for indigenous communities—it remains concerning, particularly given that women are not routinely screened for HPV, the HPV vaccination is largely inaccessible, and the majority of indigenous women have never had a pelvic examination.

Family planning knowledge and utilization is also limited, particularly in rural areas. The number of lifetime births a woman would be expected to have based on current age-specific rates, known as the total fertility rate (TFR), has recently declined from 5.6 in 1987 to 4.4 in 2002 (Ishida et al., 2012). However, despite this decline, Guatemala continues to have the largest wealth-related disparities in total fertility in Latin America, with a TFR of 4.5 for indigenous women and 3.1 among Ladina women (Ishida et al., 2012). This disparity is reflected in knowledge, access, and utilization of contraception. One study found that although 64% of indigenous women reported that they did not wish to have children in the next two years, only 10% have access to contraception (Guttmacher Institute, 2008). A survey done in 2008 of a primarily indigenous Kaqchikel Maya population (98% Kaqchikel, 2% Ladino) found that 43%

of women and 35% of men reported that they were unaware of any birth control methods (Dearden, 2008). This survey found that 45% of sexually active respondents reported using a birth control method; interestingly, this percentage decreased to 27% for women who do not work outside of the home (Dearden, 2008). A recent analysis of contraceptive utilization broke down the factors contributing to disparities between indigenous and Ladina women. In this study, language was found to be a significant barrier to contraceptive utilization: Spanish-speaking indigenous women were more likely to have utilized contraception than non-Spanish-speaking indigenous women. Indigenous women were also more likely than Ladina women to live in rural areas, live in the lowest household wealth quintile, lack electricity, and have had no schooling—all factors associated with decreased contraceptive use (Ishida et al., 2012).

There are many factors contributing to the lack of utilization of family planning services. According to Dalila de la Cruz, the education coordinator at APROFAM, the largest provider of reproductive health services in Guatemala, the primary reasons that women do not use birth control are lack of access, lack of reproductive health education, and concerns about side effects (Replogle, 2005). One common misconception about birth control is that it causes cancer and/or infertility (Adams & Hawkins, 2007). Religious reasons are occasionally cited as a reason that women do not use birth control; however, per De la Cruz, this is not often the main reason (Replogle, 2005). Frequently women report that they are either unable to use birth control due to their husband's objections or that they must hide their utilization of birth control from their partner. This is concerning, as a woman's decision-making power has been shown to be correlated with fertility and health outcomes (Becker, Fonseca-Becker, & Schenck-Yglesias, 2006). A recent study of Guatemalan husbands' and wives' decision-making power, focusing primarily on decisions regarding pregnancy, found that in couples in which the woman has no education, a larger proportion reported that the wife defers to the husband than when the wife is

educated (Becker et al., 2006). These observations likely apply to decisions regarding family planning and cervical cancer screening as well, and indicate a need to consider both partners when discussing reproductive health issues.

### *Wuqu' Kawoq – Maya Health Alliance: History and Communities Served*

Wuqu' Kawoq – Maya Health Alliance is a nonprofit NGO dedicated to providing health care in Maya languages in Guatemala, particularly Kaqchikel and K'ichee'. The work forming the basis of this thesis has been conducted in association with Wuqu' Kawoq and its partner communities. Wuqu' Kawoq has formed alliances with local community organizations (such as ACOTCHI, the Association of Traditional Midwives of Chimaltenango) to develop primary care programs, largely in child nutrition, chronic disease management, water and sanitation, and prenatal care. All programs are shaped by the community and supported by a local women's committee, with a commitment to providing linguistically and culturally appropriate services. Expansion of women's health initiatives have been a focus of the organization in 2013, particularly cervical cancer screening, STI treatment, and family planning, as well as education regarding these topics. These efforts have been focused on four rural communities located in the highlands of Guatemala, specifically within the departments of Chimaltenango and Sololá. These communities consist of primarily indigenous Maya families, including many monolingual Kaqchikel or K'ichee' speakers. A large number of women in these communities wear traditional dress (*corte*). Subsistence farming and construction work are primary sources of income for many of these families, and unemployment is common. Many men migrate to other regions of Guatemala in search of employment, often returning on a weekly to monthly basis. Others seek employment in the United States, frequently incurring significant debts in the process, particularly for those who never reach the United States or face deportation shortly after arrival.

Specific demographic data on three of these four communities is available from internal data collection by Wuqu' Kawoq; this data is unpublished and primarily for programmatic use.

Highlights from this data are found below:

1. Community One (home of 20 participants): This is a K'ichee'-speaking community with approximately 700 inhabitants. There is a relatively high rate of Spanish fluency, and it is fairly affluent compared to other highland communities. Many men from this community have migrated to the United States for employment and send remittances to their families.

Occupations of occupants over 15 years of age include: 41% homemaker, 14% students, 5% construction, 5% agriculture, 2% weaving, <1% secretary, 2% teacher, and 23% other. Global literacy rates for over 15 years of age were 77% for reading and 23% for writing. 23% had no schooling, 50% had completed elementary school, 13% middle school, 13% high school/trade school, and 0% higher education. On USAID's Quick Poverty score (United States Agency for International Development [USAID], 2008), 2.3% of households live on less than \$1 USD per day and 28% live on less than \$2 USD per day. The average number of pregnancies per woman was 4.2 and the average family size was 5.48, with 14% of the population under age 5. 63% reported no utilization of contraception, 15% reported using the rhythm method, 18% used birth control pills, 3% used an intrauterine device (IUD), 22% used Depo Provera injections, and 1% used condoms. (Note: some women have utilized multiple forms of birth control, which is why the summation of these percentages is greater than 100%). This data was collected during door-to-door surveys in June 2011.

2. Community Two (home of 16 participants): This is a fairly isolated Kaqchikel-speaking community, located a 45-minute pick-up ride over unpaved roads from the nearest city. The total population was 322 in 2009. Wuqu' Kawoq has been working for the longest period of time in this community, over 5 years. Occupations of occupants over 15 years of age include:

34% homemaker, 28% laborer, 21% weaving, 15% agriculture, 1% carpenter, and 1% nurse. 50.8% had no schooling, 20% completed some elementary school, 23.7% completed elementary school, 2.54% completed middle school, 0.85% high school/trade school, and 0% higher education. 11.1% of the population was under age 5. 77% reported no utilization of any method of contraception, 21% reported using birth control pills, 19% reported using condoms, 8% reported using lactation as a form of contraception, 5% used the implant/Nexplanon, 13% reported use of Depo Provera injections, and 10% used operations. (Note: some women have utilized multiple forms of birth control, which is why the summation of these percentages is greater than 100%). This data was collected during door-to-door surveys in November 2009.

3. Community Three (home of 10 participants): This is a Kaqchikel-speaking community that is fairly isolated from larger cities, located about a 45-minute bus ride from the nearest city. The population is made up of about 1300 inhabitants. Occupations of occupants over 15 years of age include: 38% agriculture, 42% homemaker, 8% students, 5% construction, 3% weaving, and 6% other. Global literacy rates for over 15 years of age were 76% for reading and 25% for writing. 23% had no schooling, 62% had completed elementary school, 10% middle school, 5% high school/trade school, and 0% higher education. On USAID's Quick Poverty score (USAID, 2008), 5% of households live on less than \$1 USD per day and 45% live on less than \$2 USD per day. The average number of pregnancies per woman was 4.9 and the average family size was 6.74, with 15.5% of the population under age 5. 77% reported no utilization of any method of contraception, 17% reported using the rhythm method, and 7% reported use of Depo Provera injections. This data was collected during door-to-door surveys in June 2011.

The fourth community, home of 15 participants, is similar to all of these communities in terms of socioeconomic status and education levels. It is a recently displaced community, and members speak a mixture of Kaqchikel and K'ichee', with varying degrees of Spanish fluency. This is a

small community, and nearly all women participated in the women's health course. Wuqu' Kawoq became involved in this community through the invitation of another NGO; for this reason, as well as the small size of the community, a formal needs assessment was not completed and therefore demographic data is not available for this community. In all four of these communities, there is a great need and desire for women's health programs and education.

### *State of the Field: Women's Health Education Initiatives Worldwide*

Worldwide a woman's education level has been shown to be associated with decreased fertility rates, as well as with improved health outcomes for families (Becker et al., 2006). Given the connection between education and health outcomes, health education is an essential component of many comprehensive health initiatives. Although a number of organizations are currently implementing women's health education programs, there is a paucity of literature on the efficacy of women's health education in Guatemala.

Much of the scholarly writing worldwide on women's health education centers on improving cervical and breast cancer screening rates, particularly in minority communities. The difficulties of designing and evaluating education studies have been described as well, given the need for an effective educational program to adapt to "the problem, population, and circumstances in which it is implemented" (Green, 1977). This need for adaptation limits the generalizability of these studies; however, although these studies focus on different populations, it is informative to examine the evidence regarding women's health education around the globe.

A number of studies have focused on specific interventions for targeted minority groups, particularly within the United States. A review of 63 separate interventions seeking to increase pap smear utilization found that the majority of interventions are effective, but with "tremendous variability" in efficacy (Yabroff, Mangan, & Mandelblatt, 2003). One large study among

Eastern-band Cherokee Indian women in North Carolina utilized the Solomon Four-Group design (a randomized controlled study model which eliminates bias from the effect of pre-testing) to show that women who received an individualized education program centered on cervical cancer screening were more likely to obtain pap smears after the program, without a significant change in cervical cancer knowledge (Dignan et al., 1996). A separate study employing the same model but focused on women of Lumbee Indian descent found that a one-on-one education intervention resulted in improved knowledge and utilization of pap smears (Dignan et al., 1998).

One strategy is linking screening and education initiatives to extant community organizations. In South Carolina, there have been movements to link cervical cancer screening efforts to churches in order to better reach the African-American community. These movements have focused primarily on the HPV vaccination and youth involvement, but have found that linking these interventions to church has been effective (Scarinci et al., 2010). Similar approaches have been used in faith-based pap smear campaigns in rural Appalachia, with positive results (Studts et al., 2012). Studies such as these emphasize the importance of understanding the cultural setting and population being targeted.

Training lay members of the community as community health workers is another frequently utilized strategy, with a focus on offering culturally sensitive care from a trusted source (Scarinci et al., 2010). A study of Vietnamese-American women found that lay health workers were very effective in increasing rates of both mammography and cervical cancer screening among the intervention population (Bird et al., 1998). Similarly, a randomized trial of an educational intervention for women of Hispanic descent led by community health workers (*promotoras*) demonstrated improved cervical cancer knowledge and pap smear utilization (O'Brien et al., 2010).

Other studies have emphasized the importance of overcoming language barriers, particularly within the non-English-speaking population in the United States (Scarinci et al., 2010; Hiatt et al., 2001). Access to health care, including a regular clinic and health insurance, was found to be highly associated with appropriate cancer screening and more effective than educational interventions in various underserved populations (Hiatt et al., 2008). A recent study done among Chuukese women in Hawai'i found several common themes in barriers to appropriate cancer screening: fear, privacy, lack of access to reproductive health information, and cultural beliefs. From their findings, they felt that cervical cancer education should be done in a group setting with other women, with a focus on discussing these barriers to care (Wong & Kawamoto, 2010).

Overall, this is a highly varied field of research, with many different study populations and educational models. The majority of studies focus on the efficacy of educational interventions on improving cancer screening rates for underserved populations within the United States, and various interventions have been effective in this goal. A common theme of successful interventions is the importance of offering programs in culturally-sensitive and language-appropriate formats. Employing community health workers who have a similar cultural background to participants is a commonly-used and effective strategy. Offering educational interventions without improving access to care also appears to be ineffective, indicating the need for a comprehensive approach.

### *Purpose of Inquiry*

The objectives of this pilot study are to assess the current state of women's health knowledge in four indigenous communities in rural highland Guatemala and to evaluate the efficacy of Wuqu' Kawoq's women's health curriculum in terms of improving women's health knowledge as well as promoting behavior change, particularly cervical cancer screening and family planning



utilization. We hypothesized that a comprehensive, culturally appropriate women's health course focusing on cervical cancer, family planning, sexually transmitted infections, and reproductive anatomy, offered in the community's primary language, will improve participants' women's health knowledge as well as increase utilization of family planning and cervical cancer services.

## **METHODS**

### *Institutional Review Board*

This study was reviewed by the Partners Human Research Committee Institutional Review Board and was approved for IRB exemption, Protocol #: 2013P001182/BWH.

### *Participant Selection*

The study was based in four rural indigenous communities where Wuqu' Kawoq offers primary health care services. All women in these communities were offered access to the women's health course. Participants for the classes were recruited primarily through community meetings and with the help of community-based women's committees. The course offering was also announced at Wuqu' Kawoq medical clinics; however, whether or not a woman chose to participate in the course had no impact on her ability to receive medical services from Wuqu' Kawoq. All participants in the women's health course were eligible but not required to participate in the study, with exclusion only if participants missed more than three classes of the seven-class series.

### *Participant Enrollment*

All participants in the women's health class were eligible for enrollment in the study. Participants were advised that their participation was voluntary, that they may participate in the women's health course regardless of whether or not they participate in the study, and that their responses were anonymous to protect their confidentiality. Although participants' names were recorded at the pre- and post-tests in order to compare individual participants' improvements, all identifying information was removed and replaced with a randomized assigned number to protect participants' privacy.

Initially 80 participants were identified and offered the pre-test. Of those 80, 19 did not continue with the course, did not attend more than three classes, or chose not to participate in the post-test. 61 total participants attended more than three classes and completed both the pre-test and post-test. Reasons for not continuing with the course were most frequently due to lack of time, inability to attend classes due to family commitments or illness, or moving to a different community. The 80 women initially interviewed ranged in age from 17 to 67, with an average age of 33.3. The 61 women who completed the pre-test and post-test ranged in age from 19 to 67, with an average age of 33.1. Specific demographic information about these women other than age was not collected.

Although demographic data for the participants was not collected, they were from four different communities where Wuqu' Kawoq has worked for several years. The overall demographics of these communities were described in the introduction.

### *Description of Intervention*

The intervention was a seven-week women's health course taught by a nurse educator employed by Wuqu' Kawoq in either Kaqchikel or Spanish, depending on the preference of the participants. Classes ranged in size from 5 to 15 participants, depending on the preference of community members. This data is derived from seven different groups who participated in the course.

The course was designed to be linguistically and culturally sensitive. To achieve these goals, the course was taught by a nurse educator of Kaqchikel Maya descent who is fluent in both Kaqchikel and Spanish. Literacy was not expected of participants, and course materials were designed around images rather than written information. The class schedule was set by the community, with meetings either on a weekly, biweekly, or monthly basis. Each class lasted

approximately two hours and was structured as follows: a review of the previous week's topics, followed by an interactive presentation of the topic for the day, and concluding with a review of the topic of the day in game format. At the end of each class, participants were asked for feedback on the quality of the lesson.

The format and themes covered by the course were based on the curriculum of a previous women's health course developed by Wuqu' Kawoq, which had received positive feedback from participants. Prior to beginning the course, individual open-ended interviews as well as a focus group were conducted with the women's committee from each community. These interviews and focus groups were conducted to learn more about the baseline level of women's health knowledge as well as the goals of each women's committee. Based on the information gathered in these sessions, the curriculum of Wuqu' Kawoq's women's health course was modified. For example, the topic of breast cancer was added to the curriculum at the request of the women's committees. The course was also subject to ongoing quality improvement, with frequent meetings between the author, the nurse educator, and other members of Wuqu' Kawoq staff to discuss ways to improve the course. However, the structure of the curriculum remained constant throughout the course of this study.

The topics covered by the course were as following:

1. Week one: reproductive anatomy, puberty, and menstruation
2. Week two: overview of pregnancy, medication safety during pregnancy, warning signs in pregnancy
3. Week three: menopause, breast cancer, breast self-exams

4. Week four: sexually transmitted infections, cervical cancer, cervical cancer screening/pap smears
5. Week five: family planning, including an overview of available methods (“natural” methods such as the calendar-based and cervical mucus methods, condoms, birth control pills, Depo Provera injections, IUDs, Nexplanon, tubal ligation, vasectomy)
6. Week six: domestic violence, types of abuse, with a focus on dialogue among participants about experiences in the community and ways to intervene or support one another
7. Week seven: review of course topics in which participants divide into groups and present back the six themes described above.

Each participant received a copy of a 22-page book of materials created by Wuqu’ Kawoq staff members. These materials consisted of primarily images corresponding to the six didactic classes and served as a reference for participants.

### *Knowledge Assessments*

Participants were given a one-on-one verbal 10-item knowledge assessment prior to initiation of the course. Wuqu’ Kawoq staff were trained to administer the verbal knowledge assessment by the author, and they offered the assessment in either Kaqchikel or Spanish, depending on the participant’s preference. The same assessment was then used as a post-test assessment and performed within 1 week to 3 months after the completion of the course, depending on participants’ availability.

The questions were developed by the author of the study based on themes determined to be important for basic women’s health knowledge. These themes were largely derived from initial open-ended interviews and focus groups with the women’s committees in each community.

Questions were all yes/no or open-ended questions, with an emphasis on open-ended rather than multiple choice questions in order to determine if participants were able to generate the correct response. The knowledge assessments were offered orally in either Kaqchikel or Spanish, depending on the participant's preference. Answers were scored according to a pre-determined rubric, with a total score of 10 points.

The assessment questions and scoring rubric were as follows. Each question was worth one point (see Appendix 1 for Spanish version):

1. What are the names of these parts of the body? (Blank diagram with spaces to label uterus, cervix, ovaries, Fallopian tubes, and vagina) *(0.2 points per correctly labeled item, 1 point possible)*
2. What are three types of birth control used in Guatemala? (Possible answers: birth control pills, intrauterine devices (IUDs), condom, implant/Nexplanon, Depo Provera injection, "natural" method, tubal ligation, vasectomy) *(0.3333 points per correctly identified method of birth control, 1 point possible)*
3. What is a pap smear for? (Correct answer: to screen for cervical cancer) *(1 point possible if participant mentioned uterus/cervix and cancer; 0.5 points given if mentioned either cancer or uterus/cervix; 0 points if neither)*
4. Is it normal to have vaginal bleeding after menopause? *(1 point if correctly answered no; 0 points if answered yes)*
5. Is clear vaginal discharge normal? *(1 point if correctly answered yes; 0 points if answered no)*

6. What are two signs/symptoms of a sexually transmitted infection? *(0.5 points given per correct answer, 1 point possible. Accepted answers: pain on urination, vaginal itching, change in vaginal discharge, genital lesions, pelvic pain)*
7. Do you believe that birth control causes cancer? If yes, please indicate which birth control method. *(1 point if answered no, 0 points if answered yes)*
8. Is it possible to have children after using birth control? *(1 point if answered yes, 0 points if answered no)*
9. What can be done to prevent sexually transmitted infections? *(1 point possible; 1 point if said either use condoms or abstinence/remain faithful to your partner; 0 points if none of the above)*
10. Is it possible to transmit HIV by kissing? *(1 point if answered no, 0 points if answered yes)*

#### *Utilization of cervical cancer screening and family planning services*

At the time of both the pre-test and post-test knowledge assessments, participants were also surveyed as to whether or not they had ever had a pap smear (cervical cancer screening) or utilized family planning services. This information was kept confidential, as the assessments were de-identified after administering the post-test.

#### *Statistical Analysis*

Pre-test knowledge and rates of cervical cancer screening and family planning utilization prior to the course were used as the control. The primary endpoint was improvement in overall knowledge assessment scores from baseline. Secondary endpoints include rates of reported cervical cancer screening and family planning usage. R Studio was used for statistical analysis, which included a paired t-test for the primary endpoint, and McNemar's test for the secondary endpoints. A two-tailed p-value of less than 0.05 was considered statistically significant.

### *Participant Observation*

Throughout the duration of the course, the author of this thesis attended and observed the classes in session over the period of February to November of 2013. The author attended approximately two-thirds of the individual classes offered. Initially the author attended primarily for quality assurance purposes, to ensure that the nurse educator was appropriately teaching the aforementioned curriculum. Occasionally the author would participate in order to answer specific questions; however, the majority of the time the author was simply an observer. As the nurse educator gained more expertise in the material offered, the author no longer participated often in the course and took on an observatory role. No notes were taken during the class and no recordings were made; however, the author wrote field notes afterwards. This period of participant observation provided insights into beliefs and practices regarding women's health.



## RESULTS

### *Knowledge Assessment: Overall*

61 total participants were evaluated, with a mean pre-test score of 5.46 points out of 10 total possible points, or 54.6%. The mean post-test score was 8.37 points out of 10 total possible points, or 83.7% ( $p < 0.0001$ ). Individual test scores for each participant can be found in Figure 1.

### *Knowledge Assessment: Female Reproductive Anatomy*

Question one of the knowledge assessment consisted of a blank diagram with spaces to fill in the names of the following reproductive organs: vagina, uterus, ovary, cervix, Fallopian tube. Each correct label was worth 0.2 points.

The mean pre-test score on this question was 0.27 points out of 1 point possible, as compared to the mean post-test score of 0.64 points out of 1 point. Participants were most likely to correctly identify the ovary (41% and 75.4% of participants correctly identified the ovary on pre-test and post-test respectively), followed by the vagina (31% on pre-test and 72.1% on post-test) and uterus (37.7% on pre-test and 77.0% on post-test). The cervix (13.1% on pre-test and 47.5% on post-test) and Fallopian tubes (13.1% on pre-test and 47.5% on post-test) were more difficult for participants to identify. These results can be seen in Figure 2.

### *Knowledge Assessment: Familiarity with Birth Control Methods*

On question two of the knowledge assessment, participants were asked to name three types of birth control used in Guatemala. On the pre-test assessment, 73.8% of participants were able to name three types of birth control, 16.4% were able to name two types, 3.3% were able to name one type, and 6.56% reported no knowledge of any birth control methods. On the post-test assessment, 91.8% were able to name three forms of birth control, 6.6% named two methods,

1.6% named one type of birth control, and no women were unable to name at least one birth control method. See Figure 3 for a graph of these results.

There were 7 types of birth control mentioned: Depo Provera injections, birth control pills, condoms, implant/Nexplanon, IUDs, operations (not specified between tubal ligation and vasectomy), and “natural” methods (referring to both calendar-based and cervical mucus-based methods). The most commonly mentioned was Depo Provera injections, with 58 women in the pre-test and 55 women in the post-test naming this method. Birth control pills were the second most commonly named, with 53 women in the pre-test and 52 women in the post-test. Condoms were named by 17 women in the pre-test and 29 in the post-test, IUDs were named by 15 in the pre-test and 14 in the post-test, “natural” methods were named by 13 women in the pre-test and 12 in the post-test, operations were named by 5 women in the pre-test and 10 in the post-test, and the implant/Nexplanon was named by 6 women in the pre-test and 3 in the post-test.

#### *Knowledge Assessment: Understanding of Pap Smears*

In question three of the knowledge assessment, women were asked to explain the purpose of pap smears. One full point was awarded if participants correctly identified that pap smears are used to detect cancer of the cervix (often referred to simply as the “uterus” by both participants and health care providers in Guatemala). Half a point was awarded for either mentioning “cancer” or “uterus/cervix.” No points were awarded for any other explanations.

In the pre-test, 31.0% of women were awarded one point for a full explanation; in the post-test, 54.1% of women were able to fully explain the purpose of pap smears. Of the rest of the participants, 18% mentioned “uterus/cervix” and 21.5% mentioned “cancer” during the pre-test, and the remaining 27.9% offered either incorrect answers or reported not knowing the answer. During the post-test, 13.1% mentioned “uterus/cervix” and 18% mentioned “cancer”; the

remaining 15% either responded incorrectly or reported not knowing the answer. These results can be seen in Figure 4.

#### *Knowledge Assessment: Risk of Post-Menopausal Bleeding*

In question four of the knowledge assessment, participants were asked if it was normal to have vaginal bleeding after menopause. During the pre-test, 82% correctly answered no, 8.1% answered yes, and 9.8% did not know. In the post-test, 100% of participants correctly responded no. These results are shown in Figure 5.

#### *Knowledge Assessment: Beliefs on Physiologic Discharge*

Question five asked participants if it is normal to have clear vaginal discharge. One point was awarded for answering yes. In the pre-test 42.6% of participants responded yes, 41% no, and 16.4% did not know. In the post-test 77% responded correctly with yes, 21.3% responded no, and 1.6% did not know. These results are shown in Figure 6.

#### *Knowledge Assessment: Symptoms of Sexually Transmitted Infections*

In question six, participants were asked to name two signs or symptoms of sexually transmitted infections (STIs). Half a point was awarded for each correct answer. Accepted answers included: burning or pain on urination, pelvic pain, abnormal vaginal discharge, genital ulcers/lesions, and pruritus. In the pre-test, 37.7% of participants were able to identify two possible STI symptoms, 18% identified one, and 44.3% were unable to identify any. In the post-test, 62.3% identified two symptoms, 23% identified one, and 14.8% did not identify any correct symptoms. Results from this question are shown in Figure 7.

#### *Knowledge Assessment: Link between Birth Control and Cancer*

Question seven of the knowledge assessment asked, “Does birth control cause cancer?” Women were awarded one point for answering no. If they responded yes, they were asked to identify which type of birth control caused cancer. In the pre-test, 45.9% responded yes, 32.8% responded no, and 21.3% did not know. In the post-test, 96.7% responded no, 3.3% responded yes, and no participants reported not knowing. Of the types of birth control cited as responsible for causing cancer, birth control pills were mentioned most frequently (ten times), followed by Depo Provera injections (mentioned five times), and IUDs (mentioned once). These results can be seen in Figure 8.

#### *Knowledge Assessment: Link between Birth Control and Infertility*

In question eight of the knowledge assessment, participants were asked if it is possible to have children after using birth control. One point was awarded for answering yes. In the pre-test, 85.2% responded yes, 6.6% responded no, and 8.2% did not know. In the post-test, 95.1% responded yes, 3.3% responded no, and 1.6% did not know. These results are shown in Figure 9.

#### *Knowledge Assessment: Preventing Sexually Transmitted Infections*

Question nine of the knowledge assessment asked women to identify how to prevent the transmission of STIs. One point was awarded for the following answers: use condoms, abstinence, be faithful to your partner. No points were awarded for other incorrect answers; examples of incorrect answers included washing yourself well, going to the doctor, taking medicines, getting vaccines, taking vitamins, getting a pap smear, or taking care of yourself.

In the pre-test, 36% of participants answered correctly as compared to 74% who answered correctly on the post-test. Abstinence or faithfulness were listed 15 times in the pre-test and 19 times in the post-test, and condoms were listed 8 times in the pre-test and 36 times in the post-test. Responses are shown in Figure 10.

### *Knowledge Assessment: Transmission of HIV*

The final question of the knowledge assessment was, “Can HIV be transmitted by kissing?”

Initially during the pre-test assessment, 34.4% responded yes, 55.7% responded no, and 9.8% did not know. In the post-test, 6.6% responded yes, 90.2% responded no, and 3.3% did not know.

These responses can be found in Figure 11.

### *Cervical Cancer Screening*

During the pre-test assessment, 48 of the 61 participants (78.7%) reported having had a pap smear at least once in their lifetime. At the time of the post-test assessment, 56 of the 61 participants (91.8%) reported having had a pap smear at least once in their lifetime ( $p=0.013$ ).

This indicates that 8 participants obtained a pap smear at some point between the pre-test and post-test assessments. These results are graphically represented in Figure 12.

### *Family Planning Utilization*

During the pre-test assessment, 32 of the 61 participants (52.5%) reported having used birth control at some point in their lives. At the time of the post-test assessment, this number increased to 33 of 61 participants (54.1%), with one additional participant utilizing birth control at some point between the pre-test and post-test assessments ( $p=1$ ). During the administration of the assessment, this participant noted that she decided to use birth control as a direct result of what she had learned during the course. These results can be seen in Figure 12.

## **DISCUSSION, CONCLUSIONS, AND SUGGESTIONS FOR FUTURE WORK**

Great disparities exist in women's health outcomes in Guatemala, with rural indigenous women facing significant barriers to care as compared to their urban Ladino counterparts. The purpose of this study was to assess women's health knowledge in four rural indigenous communities in the highlands of Guatemala, as well as to evaluate the efficacy of a comprehensive women's health course. Both the level of women's health knowledge and women's health behaviors were assessed before and after participation in the course.

The pre-test knowledge assessments revealed several interesting patterns in beliefs regarding women's health, which will be discussed below. From this initial data, the women's health curriculum was effective in improving women's health knowledge. The course also may have positive impacts on women's health behaviors, particularly rates of cervical cancer screening; however, we are unable to draw strong conclusions regarding behavior change at this point, as a longer period of follow up and larger study sample would be required.

### *Women's Health Knowledge: Reproductive Anatomy*

One of the most challenging questions on the knowledge assessment was the first question, in which participants were asked to identify five different female reproductive organs. Initially participants identified only 1.36 of 5 total reproductive organs, most commonly the ovary. Although this increased to 3.20 correctly identified by the end of the course, this is still a fairly low number. As many women who participated in the course had limited access to formal education, they likely had little to no exposure to formal reproductive education. Some of these reproductive organs, particularly the ovary and the uterus, are frequently referenced in conversation, despite lack of understanding of the location and function of these organs. For example, according to participants, it is very common for health providers to tell women they

have “cysts” in their ovaries. We have observed that many women presenting to clinic for a pap smear incorrectly believe that ovarian cysts can be diagnosed with a pap smear. A basic understanding of reproductive anatomy is helpful when seeking medical attention, as it provides women the opportunity to ask informed questions and may improve understanding when reproductive organs are mentioned. Health professionals should be aware of the limited familiarity with reproductive anatomy found in this study when addressing reproductive health issues.

### *Women’s Health Knowledge: Family Planning*

Several questions in the knowledge assessment focused on knowledge of birth control, as lack of access to information regarding family planning has been cited as a reason for low levels of birth control utilization in Guatemala (Replogle, 2007; Guttmacher, 2008). In the second question on the knowledge assessment, women were asked to identify at least three types of birth control. Participants in this study were able to identify birth control methods at a fairly high rate, with 73.8% able to identify three types of birth control and only 6.56% unable to identify a single method. As these participants were drawn from communities where Wuqu’ Kawoq has been working for several years, it is possible that they have had more exposure and access to birth control than women in other communities. The rate of birth control utilization in these communities, ranging from 7% to 23% from baseline demographic data, is not significantly higher than 10% cited elsewhere for indigenous communities (Guttmacher, 2008); however, this baseline data is several years old and efforts have been made in that time to improve access to and utilization of birth control in these communities, so it is likely that these numbers have since increased. It is also very likely that the elevated level of birth control knowledge seen in this study is due to self-selection for participants who have an interest in women’s health, since attendance at the course was voluntary.

Of contraception methods named, birth control pills and Depo Provera injections were most frequently mentioned; this is consistent with other surveys of birth control familiarity in indigenous communities (Dearden, 2008). Of note, the number of women who mentioned condoms did increase from pre-test to post-test, which is encouraging given the lack of knowledge of condoms which has been cited elsewhere (Ikeda et al., 2013). The promotion of condom utilization is important due to the fact that condoms are the most accessible form of birth control in Guatemala that protects against STIs as well as preventing pregnancy.

Another cited reason for low levels of family planning utilization is fear of side effects. A common belief among women in rural Guatemala is that birth control causes cancer (Adams & Hawkins, 2007). This belief was echoed by the results of our knowledge assessment, with nearly half of respondents initially reporting that birth control causes cancer, particularly birth control pills and injections. During the course, several women shared that they had learned this from neighbors, relatives, and even church leaders. Many women feared that birth control pills in particular accumulate in the uterus and give rise to cancer. Given the prevalence of this belief, a concerted effort was made during the course to explain that birth control does not cause cancer. Women were given the opportunity to share the stories that they had heard and discuss their concerns, and then the course instructor addressed these issues. One particularly effective strategy was an interactive demonstration in which the course instructor dissolved pills in water to show that birth control pills do not accumulate but rather enter the body systemically. After the course, nearly all (96.7%) participants correctly reported that birth control pills do not cause cancer. However, it is difficult to determine whether participants truly believed what was taught or if they simply stated what they had been taught in the class without fully believing it.

Another cited misconception about birth control is that it leads to infertility (Adams & Hawkins, 2007). According to the pre-test knowledge assessments, although this belief is held by some



women, 85.2% of participants believed that a woman could still have children after using birth control. This increased to 95.1% in the post-test assessment. Of note, another misconception about birth control frequently mentioned during the course but not explicitly studied in the knowledge assessment is the belief that when a woman uses Depo Provera injections, she ceases to menstruate and as a result the menstrual blood accumulates in the body. Many participants feared that if they were to use Depo Provera and then stop, all of this accumulated blood would be expelled and they would suffer from a severe vaginal hemorrhage. Beyond these fears, there are certainly other factors contributing to a woman's choice to use birth control or not. Many women shared concerns that their husbands would not approve of family planning, while others reported that birth control is against their religious beliefs. These factors should all be taken into consideration when designing a women's health intervention.

#### *Women's Health Knowledge: Cervical Cancer Screening*

As discussed previously, cervical cancer is the second most common cancer diagnosed in women in Guatemala, largely due to underutilization of cervical cancer screening services (GLOBOCAN, 2012). Of the women in our study, less than one-third of women were able to correctly identify the purpose of pap smears prior to taking the course. Even after the course, this number only rose to 54.1%, which is less of an improvement than we saw in many of the other categories of questions. This indicates a need for reevaluation of our teaching style when discussing cervical cancer screening to determine if a different tactic leads to increased understanding.

Lack of understanding of the purpose of pap smears is likely a significant reason why women do not seek out the exam. It is interesting to note that among our participants, 78.8% had had a pap smear at least once in their life prior to participating in the course; despite having had a pap smear

previously, a significant number of these women were unable to describe the purpose of the exam. Many women thought that the primary purpose of a pap smear was to diagnose vaginal infections. While vaginal infections are occasionally discovered during pelvic exams, this explanation overlooks the importance of the test for cancer screening. The focus on vaginal infections is likely a reflection of the broader pap smear program in Guatemala. From experience with Wuqu' Kawoq's women's health clinics, a large number of pap smear reports in Guatemala list "inflammation," ranging from "light" to "severe," on the result. Guatemalan providers use this information to diagnose infections and generally treat these women with a combination of antifungal and antibiotic agents. As infections are diagnosed far more frequently than precancerous lesions on pap smears, it is not surprising that many women were unable to explain the purpose of pap smears in terms of cervical cancer prevention.

Other participants had less of a grasp of the procedure, responding with answers such as, "The pap smear is done to clean out the vagina." Several women, when asked to explain how a pap smear was done, reported that the uterus was removed from the body, examined, and then replaced. Multiple participants offered stories of a woman who believed she had contracted cervical cancer from a pap smear. Our results indicate a great need for providers to more thoroughly explain procedures, particularly exams such as pap smears which are uncomfortable and embarrassing for many women, and which need to be repeated multiple times throughout the course of a woman's lifetime.

Another concern expressed during the classes was that pap smears were unreliable, with various participants sharing stories of women who had had a normal pap smear and then were diagnosed with advanced cervical cancer only months later. These comments reflect a level of mistrust of the exam; unfortunately, in Guatemala this suspicion regarding the accuracy of pap smears may not be unfounded. According to Anita Chary, an MD/PhD candidate from Washington

University studying cervical cancer in Guatemala, there is little to no quality control in many pathology laboratories in Guatemala (personal communication, January 31, 2014). The inconsistency in quality of pap smear results and difficulty of follow-up with patients, particularly in rural areas, has also led to increased utilization of visual inspection with acetic acid and cryotherapy (VIA/cryo), an alternative method of cervical cancer screening that offers point-of-care diagnosis and treatment (Chary, 2013; Mathers, Wigton, & Leonhardt, 2005). As Wuqu' Kawoq provides comprehensive cervical cancer screening with pap smears in these communities, discussion of cervical cancer prevention focused primarily on pap smears during this pilot course. However, the changing landscape of cervical cancer screening should be considered when providing educational interventions, with a focus on the types of technologies utilized in the area.

#### *Women's Health Knowledge: Sexually Transmitted Infections (STIs)*

As access to reproductive health education is limited in rural Guatemala, understanding of and familiarity with sexually transmitted infections is lacking. As discussed previously, other studies have found this to be true as well, with a survey from 2007 showing that of 839 indigenous men and women ages 18-49, 47.6% did not know what an STI is (Ikeda et al., 2013). It is essential to address this particular issue because if a woman does not understand the symptoms of an STI, she may be less likely to know when to seek treatment. Without treatment, STIs can advance and lead to further complications, such as pelvic inflammatory disease (PID), which increases the risk of ectopic pregnancy. In our pre-test, nearly half of participants (44.3%) were unable to identify a single symptom of an STI. This improved significantly by the end of the course, with nearly two-thirds (62.3%) able to identify two symptoms.

Another common misconception among women in Guatemala is that any type of vaginal discharge, including physiologic discharge, represents an infection of some kind. This leads to overuse of antibiotics and antifungals, causing heightened exposure to potential adverse side effects and rising antibiotic resistance. This is of particular concern in Guatemala given that no prescriptions are necessary to purchase medications from local pharmacies. This belief was reflected in our pre-test results, with 42.6% believing that clear vaginal discharge, normally physiologic, is abnormal. Although this number did decrease to 21.3% by the end of the course, many women continue to believe that any form of vaginal discharge is abnormal. This is a topic that should be thoroughly addressed in educational initiatives to both raise awareness of true STI symptoms as well as prevent unnecessary treatment of physiologic findings.

Despite STIs being quite prevalent in Guatemala, as discussed previously, knowledge of STI prevention, particularly condom use, is also limited. We found that when asked how to prevent STIs, over half of participants (39 out of 61) did not know. These incorrect answers reflected common misconceptions about causes of STIs, such as poor hygiene. Others felt that taking vitamins would prevent STIs, which is reflective of the medical culture of Guatemala, where vitamin injections are often prescribed as treatment for a variety of conditions. Importantly, only 8 of the 61 participants mentioned condoms during the pre-test; this number increased to over half of the participants (36 of 61) by the end of the course. This is a significant gain, as condoms are not frequently used in Guatemala, a fact that was reflected in our baseline demographic data showing condom use ranging from 0-19% in these communities.

Throughout the course, many women noted that condoms are often associated with promiscuous behavior. This reputation should be taken into consideration when developing course materials, as de-stigmatization and normalization of condom use needs to be promoted in order for women to utilize this method of birth control and STI prevention. Another common complaint about

condoms is that men do not want to use them. As discussed previously, decision-making power is often in the hands of the husband (Becker et al., 2006), and condom use is frequently limited due to the objections of men. This emphasizes the importance of focusing family planning education, particularly condom use, on all members of the community and not solely women.

Another commonly misunderstood and stigmatized STI is HIV. Although the prevalence of HIV is unknown in these communities, studies have suggested that HIV rates in indigenous communities may be even higher than the national rate (Gracey & King, 2009). The majority of participants had heard of HIV before, but often did not have an informed understanding of the illness. On the pre-test, over one-third believed that HIV was transmissible by kissing. This shows the importance of education regarding HIV in order to decrease the associated social stigma. During the course, several women reported having heard of someone who had HIV, and the social difficulties that followed the diagnosis, including being ostracized from their family. Many women during the course expressed the belief that HIV was untreatable and was essentially a death sentence. This belief frequently carried over to other STIs, with a number of women incorrectly assuming that all STIs are untreatable. For many participants, the only STI that they had ever heard mentioned was HIV, which made the idea of an STI in general extremely frightening. These misconceptions should be taken into consideration when developing educational initiatives regarding STIs, particularly focusing on decreasing the stigma attached to STIs as well as increasing awareness of STI symptoms and potential treatments.

#### *Efficacy of Women's Health Curriculum: Women's Health Behaviors*

It is challenging to assess behavior change over a short period of time; in order to determine if there is a lasting effect in health behaviors, the participants should be followed for significantly longer. Assessing behavior change in a short period of time often leads to overlooking changes

that would be seen over time; however, there is also a risk of a “backsliding effect” in which behavior change is not maintained over time, leading to an overestimation of the efficacy of an intervention (Green, 1977).

In the course of our study, no statistically significant changes were seen in the percentage of women utilizing family planning services; however, we did identify one participant who informed us that she elected to use birth control as a direct result of the course. It is interesting to note that 52.5% of participants reported having used birth control prior to the course, which is higher than the baseline rates found for these communities (from 7-23%), as well as rates found in studies of other indigenous communities, where the figure is closer to 10% (Guttmacher, 2008). This may reflect promotion of birth control by Wuqu’ Kawoq over the last few years, as well as self-selection for participants who are interested in women’s health topics and may be more open to birth control, as participation in the course was voluntary. Given that 73.8% of participants were able to name three types of birth control, this is a population that has been exposed to birth control previously. This prior exposure also carries with it many misconceptions about birth control, as discussed previously. It would be informative to examine the efficacy of this course in a population with less prior knowledge of birth control.

Prior to the course, 48 of the 61 participants (78.7%) reported having had a pap smear at least once in their lifetime. This number increased to 56 of the 61 participants (91.8%) at the end of the course, indicating that eight women obtained a pap smear between the administration of the pre-test and post-test. The number of women who had obtained a pap smear prior to participating in the course is much higher than that reported in other studies; for example, one study noted that 78% of Mayan women aged 15-49 had never had a pelvic exam (Ikeda et al., 2013). This difference is possibly due in part to Wuqu’ Kawoq’s presence in these communities for the past several years and therefore may not reflect overall rates of cervical cancer screening

in other rural indigenous communities. It also likely reflects a self-selection for women who are motivated and interested in women's health, leading to an artificially elevated rate of cervical cancer screening. Although this initial percentage appears encouraging, it is important to note that many participants reported never receiving the results of their previous pap smears. We also did not assess if women were accessing cervical cancer screening at the recommended frequency; rather, we assessed if they had ever received a pap smear in their life. Further follow up is required to determine if women are truly obtaining adequate cervical cancer screening.

Although we did find that eight women obtained their first pap smear between the administration of the pre-test and post-test, it is difficult to determine if this was a direct result of participation in the course, as Wuqu' Kawoq offered pap smear clinics to all women in the community throughout the duration of the course. Several participants may have decided to utilize these services due to improved access to cervical cancer screening rather than increased understanding of the importance of pap smears. Wuqu' Kawoq has built a strong level of trust with each community, provides all services in indigenous languages, and offers comprehensive follow up of all abnormal results; these factors likely encouraged women who had been hesitant or skeptical of pap smears to utilize these services. As several prior studies of cervical cancer screening initiatives have focused on the importance of reliable access to care on screening rates, maintaining access to high quality women's health care is crucial to the success of an educational initiative.

#### *Efficacy of Women's Health Curriculum: Limitations*

As discussed previously, this pilot women's health course resulted in improvement in scores on the knowledge assessment, reflecting an inferred increase in women's health knowledge.

Although we have a general demographic picture of each community, we did not assess the

baseline educational background, literacy level, socioeconomic status, or primary language of individual participants. These factors may influence the degree of familiarity and comfort in a classroom setting, and may have an impact on the efficacy of the course format.

This particular group of participants also may have been more informed about women's health at baseline due to Wuqu' Kawoq's ongoing involvement in these communities. The design of the study also led to self-selection of women who are interested in women's health topics, which is reflected in the higher-than-expected levels of knowledge and utilization of birth control, for example. Given the nature of the study, however, this type of self-selection is difficult to avoid, as participants cannot be forced to attend educational sessions. Despite the inherent biases in the selection of participants, it is important to consider that even in this motivated group, misconceptions about women's health were prevalent. It is likely that a group of participants with less exposure to these topics would have more limited women's health knowledge at baseline.

In general, educational initiatives are difficult to evaluate because they are very personalized and their efficacy is dependent on the participants' investment in the program. The quality of the teacher also may impact the efficacy of an educational program, making replication of the study dependent on instructor quality. Our method of analysis using the knowledge assessment is also imperfect, as it was designed according to what the study author believed were important themes and common misconceptions among women in rural Guatemala, based on input from local women's committees. The effect of the course on women's health beliefs not included in the knowledge assessment is yet to be seen and could be more thoroughly studied. The same knowledge assessment was also repeated at the beginning and end of the course, so there may have been a degree of improvement simply due to participants becoming more familiar with the questions used. There is the possibility that exposure to the pre-test material alone may have



raised participants' awareness of particular women's health topics, leading to skewed post-test results. In future research, the Solomon Four-Group design can be employed to avoid this type of bias (Dignan et al., 1998). A weakness of this study is its overall design, as there is no separate control group and pre-test knowledge was used as the control.

### *Impact on Women's Health Education Initiatives*

The field of women's health education centers largely on interventions focused on behavior change, particularly increasing rates of cervical cancer screening. While this is an important goal, there are few studies focusing on comprehensive women's health education rather than a specific theme. These studies, while informative, frequently are focused on a specific minority population, and it is difficult to determine the degree of generalizability of the findings. This study suffers from this problem of generalizability as well; however, it does reinforce some common themes, such as barriers to cervical cancer screening and misconceptions regarding birth control methods.

In terms of women's health in Guatemala, there is a great need for improved access to reproductive education for rural indigenous communities, and a number of governmental and non-governmental organizations offer educational programs. These interventions, however, are often not assessed, and there is a paucity of literature on the efficacy of these interventions. This pilot study begins to open the discussion regarding women's health education in indigenous Guatemala, with the goal to inspire further literature on effective interventions in these communities.

### *Conclusions*

This study of women's health education in four rural indigenous communities illuminates several important issues that should be targeted in future women's health education: the common

misconception that birth control causes cancer, the lack of understanding of STI symptoms and treatment, the lack of understanding of pap smears despite many participants having had a pap smear, the lack of familiarity with condoms for STI prevention, and the misconception that physiologic vaginal discharge is abnormal. Participants in the study were found to have higher than expected rates of cervical cancer screening and birth control utilization as compared to the literature and to the baseline rates of these communities. The study also showed that a comprehensive culturally sensitive women's health course was effective in improving women's health knowledge. Although the study was carried out over a short time frame, there were encouraging trends in rates of cervical cancer screening and birth control utilization; however, it is difficult to determine if these trends were due to the course or due to the concurrent women's health clinics offered by Wuqu' Kawoq. This is a small pilot study focusing on a specific population; however, it addresses a paucity of literature on women's health education in rural indigenous Guatemala.

### *Suggestions for Future Work*

Given the lack of studies focusing on women's health education in indigenous communities in Guatemala, there are numerous areas of future work. At this time, further study of the current Wuqu' Kawoq course is on-going. Future study of this particular course will involve expanding to more communities, including communities that are new to Wuqu' Kawoq. Comparing the course to a control group would be informative, as well as implementing the Solomon Four-Group design to decrease the effects of pre-testing. A cost-benefit analysis of the course will be important for sustainability as well. It would also be informative to examine knowledge retention over time, and whether or not the timing of the post-test has an effect on post-test scores.

Modifications of the course structure could be studied to determine the effect of class size, class duration or length, and degree of interactive vs. didactic styles on course efficacy. A study examining the effect of baseline characteristics of participants, such as educational level and literacy, would also be informative for shaping further programs. Different educational models, such as individualized one-on-one interventions, may also be effective in improving women's health knowledge and should be assessed. As not all members of a community are motivated to attend a seven-week women's health course, studies of other models of women's health education are essential. Other women's health interventions discussed in the literature could also be studied in this particular population, such as offering women's health education in churches or utilizing community health workers to provide educational home visits. Classes targeted to the men of the community would also be important, given the husbands' decision-making power in reproductive health decisions.

Through participant-observation of the author, as well as responses to the pre-test, many insights were gained into women's health beliefs. However, further ethnographic interviews with women assessing women's health behaviors and beliefs would help shape further educational interventions as well as raise awareness of these issues.

## **SUMMARY**

Great disparities exist in reproductive health outcomes for rural indigenous communities in Guatemala, with women facing significant barriers to access to women's health education. This pilot study utilized a ten-point knowledge assessment along with participant observation to analyze the current setting of women's health knowledge in four rural indigenous communities. Several insights into common women's health misconceptions were identified: the belief that birth control causes cancer, a lack of understanding of STIs, and a lack of knowledge regarding cervical cancer screening. The study also evaluated a comprehensive, culturally sensitive women's health curriculum and its effects on women's health knowledge and behaviors. Pre-test and post-test scores for 61 participants in four different communities were compared, with overall improvement of scores from 54.6% to 87.3% ( $p < 0.0001$ ). Although the efficacy of the course needs to be studied for a longer period of time to show true behavior change, there were encouraging trends in the rates of cervical cancer screening and birth control utilization. The results of this pilot study address a paucity of literature on women's health education in rural indigenous Guatemala, and illuminate important issues to consider when developing a women's health program.

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## TABLES AND FIGURES

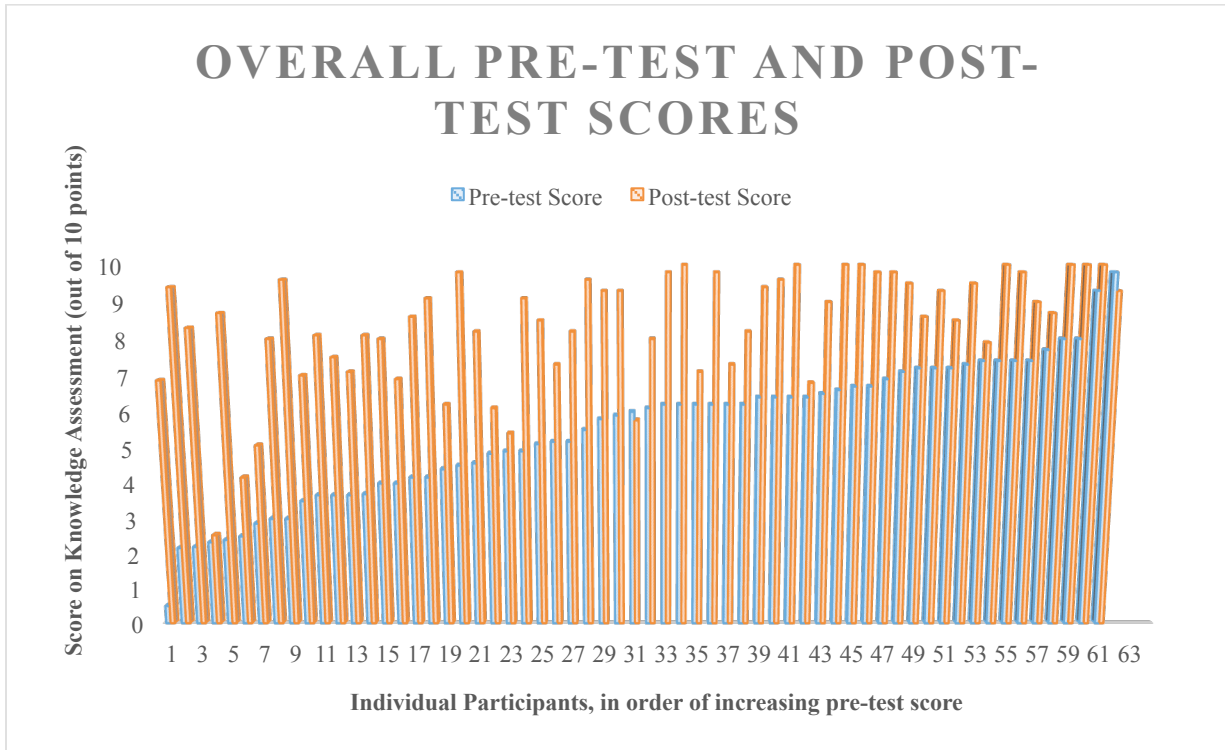


Figure 1. Overall pre-test and post-test scores out of 10 total points. This figure shows the pre-test and corresponding post-test score of each participant, listed in order of increasing pre-test score.

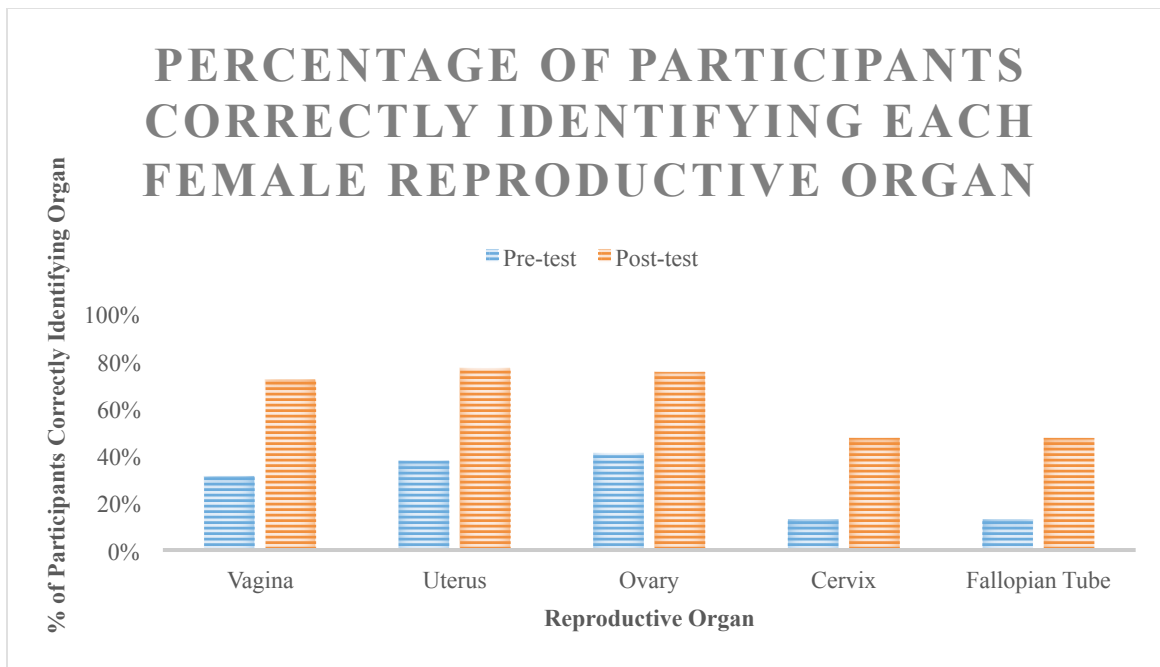


Figure 2. Responses to question 1 on the knowledge assessment: percentage of women who correctly identified each of the following reproductive organ (vagina, uterus, ovary, cervix, fallopian tube).

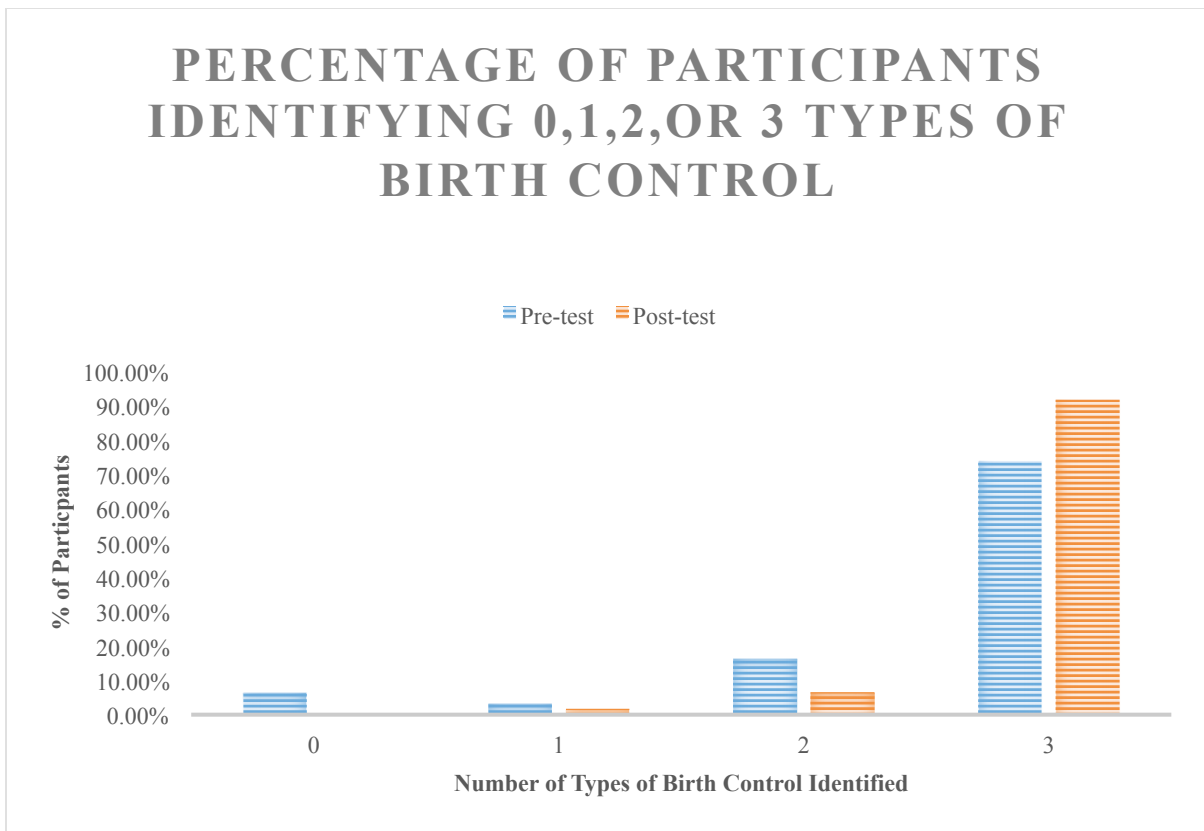


Figure 3. Percentage of participants correctly identifying 0, 1, 2, or 3 types of birth control on the pre-test and post-test.

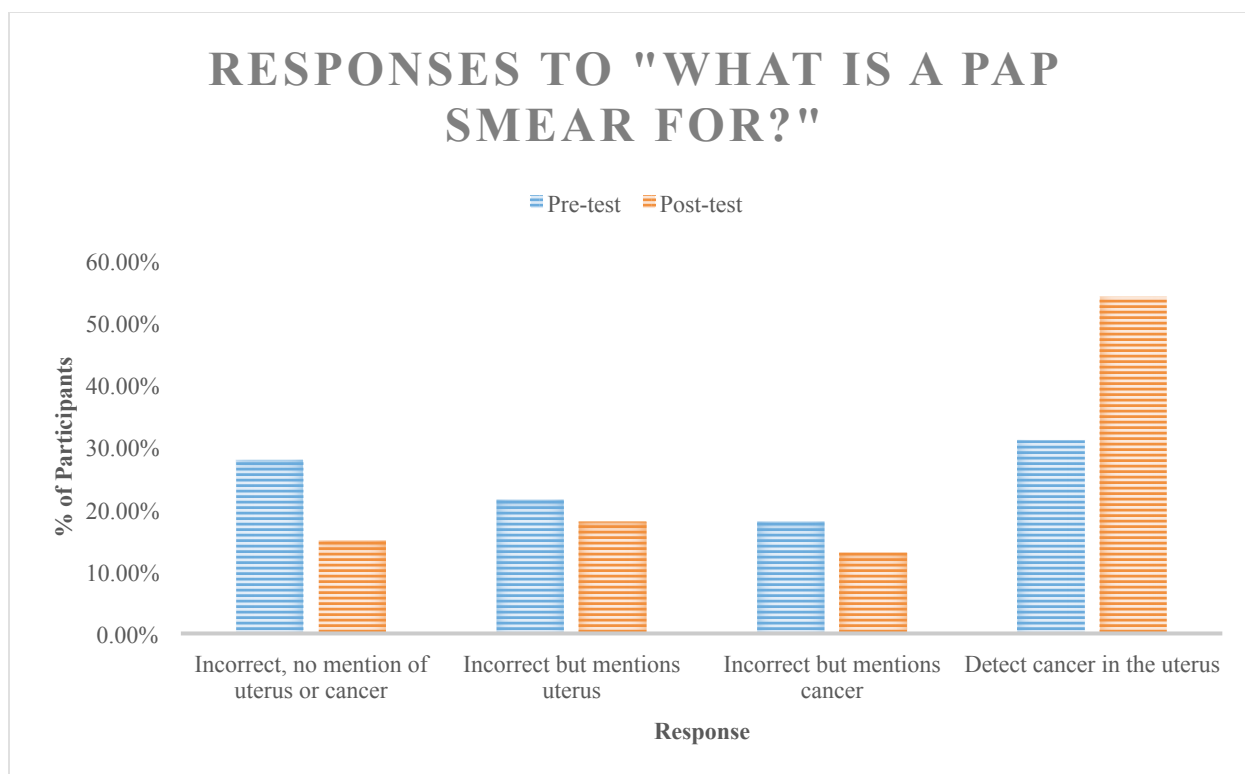


Figure 4. Responses to the question, “What is a pap smear for?”; responses divided into percentages of women who answered either incorrectly (0 points), incorrectly but with mention of “uterus” (2 points), incorrectly but with mention of “cancer” (2 points), or correctly describing detection of cancer in the uterus (3 points).

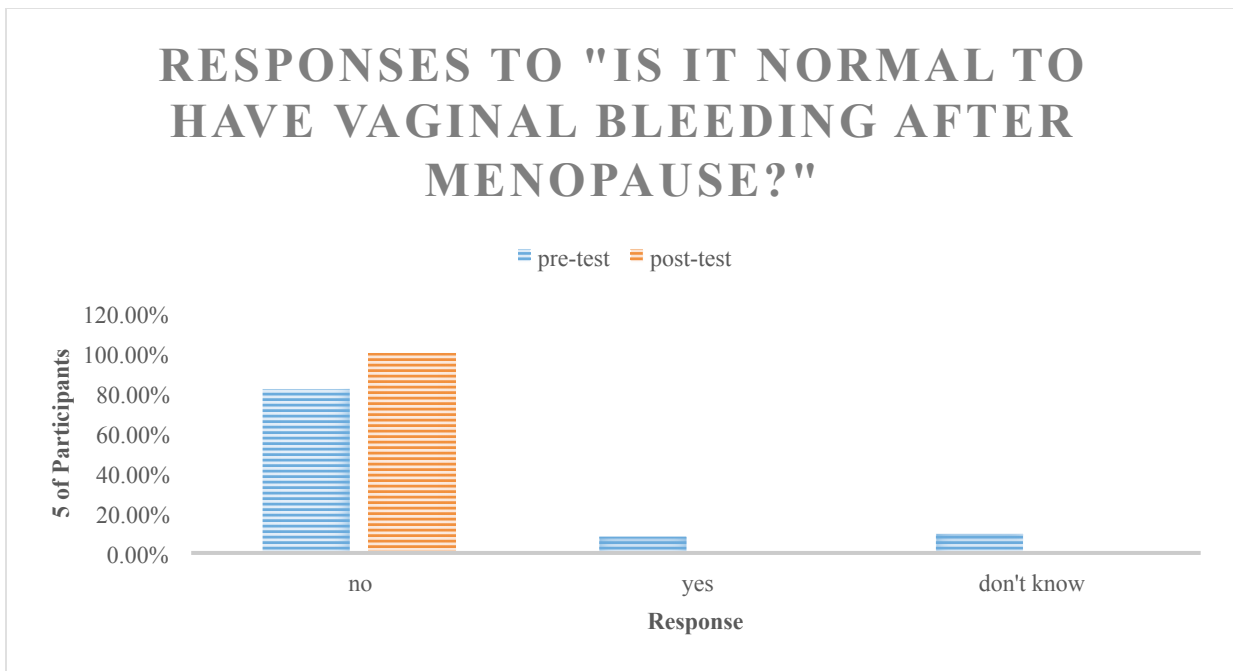


Figure 5. Response to the question “Is it normal to have vaginal bleeding after menopause?” Responses divided into no (correct), yes, or don’t know.

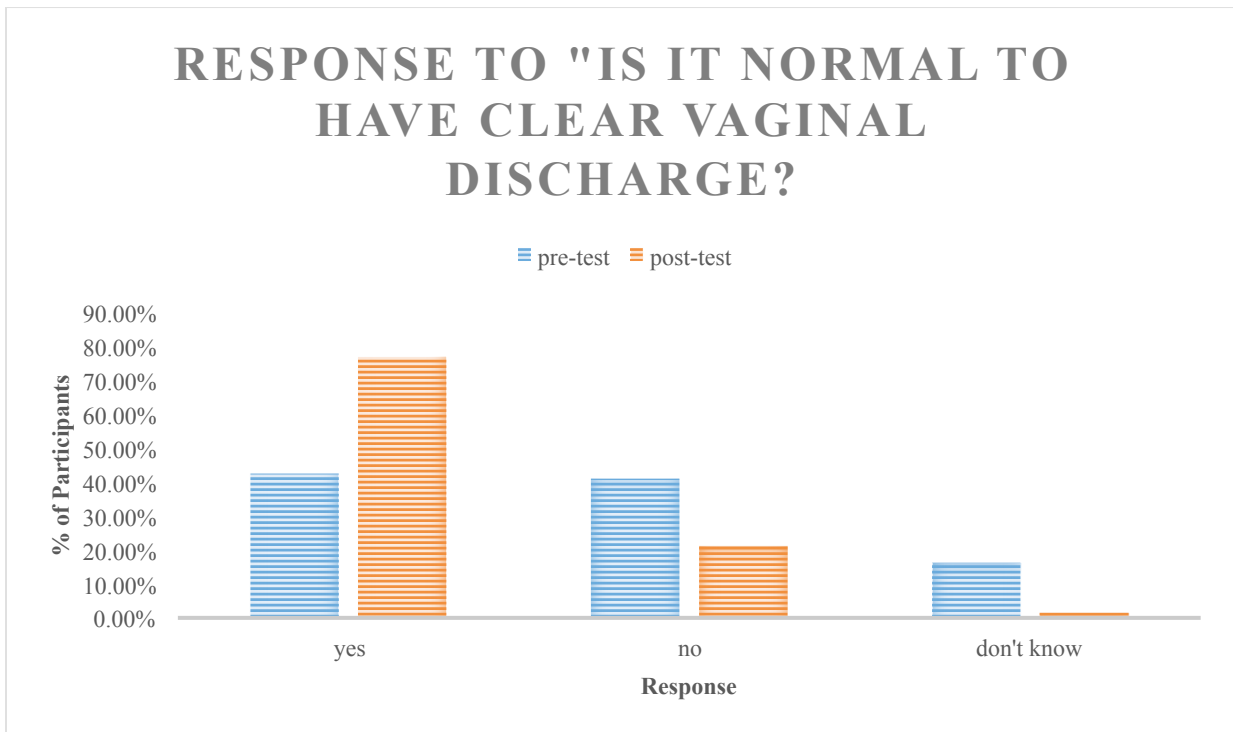


Figure 6. Responses to the question “Is it normal to have clear vaginal discharge?” Responses divided into yes (correct), no, or don’t know.

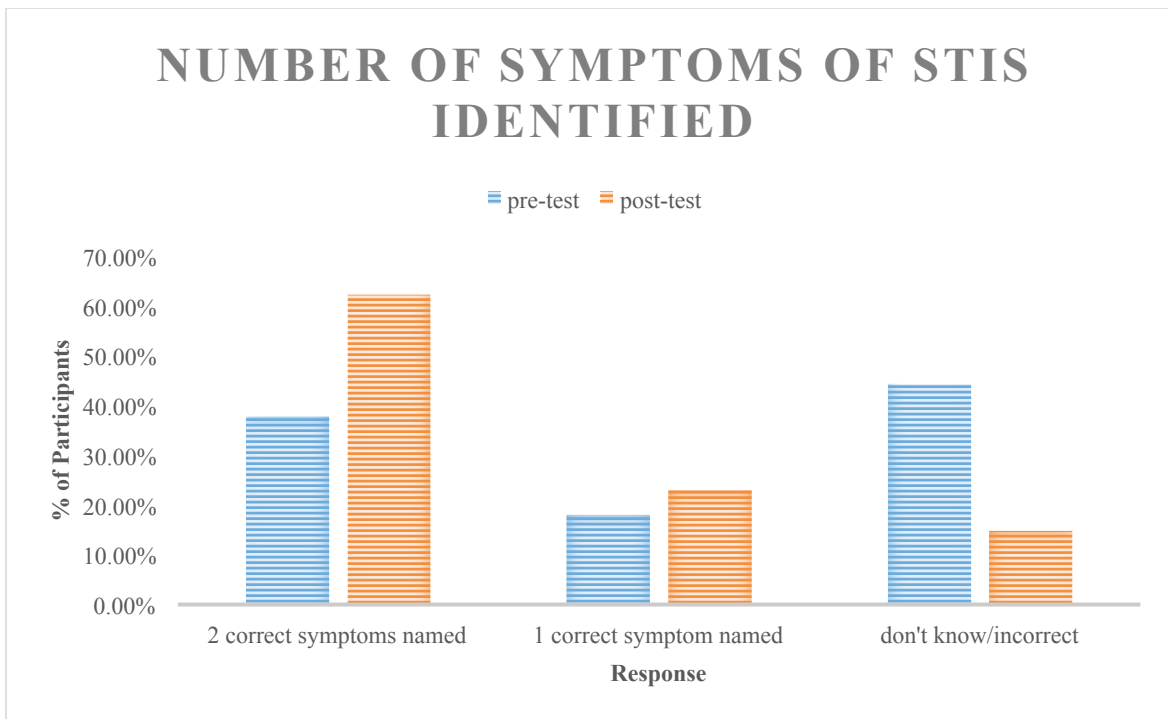


Figure 7. Number of symptoms of STIs correctly identified by participants.

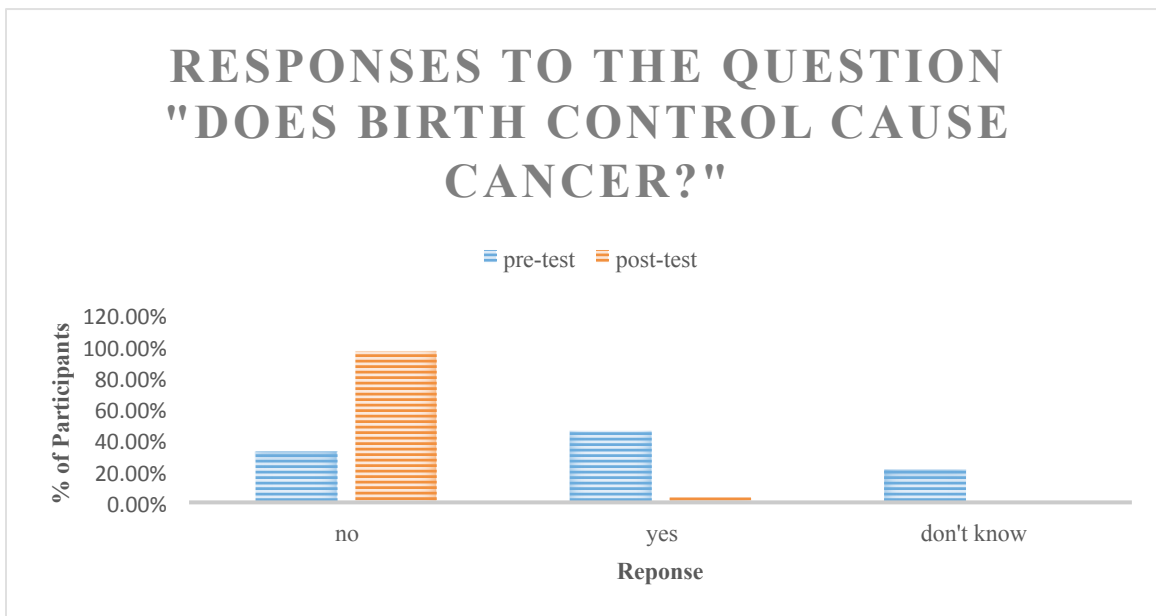


Figure 8. Responses to the question, "Does birth control cause cancer?" by percentage of participants.

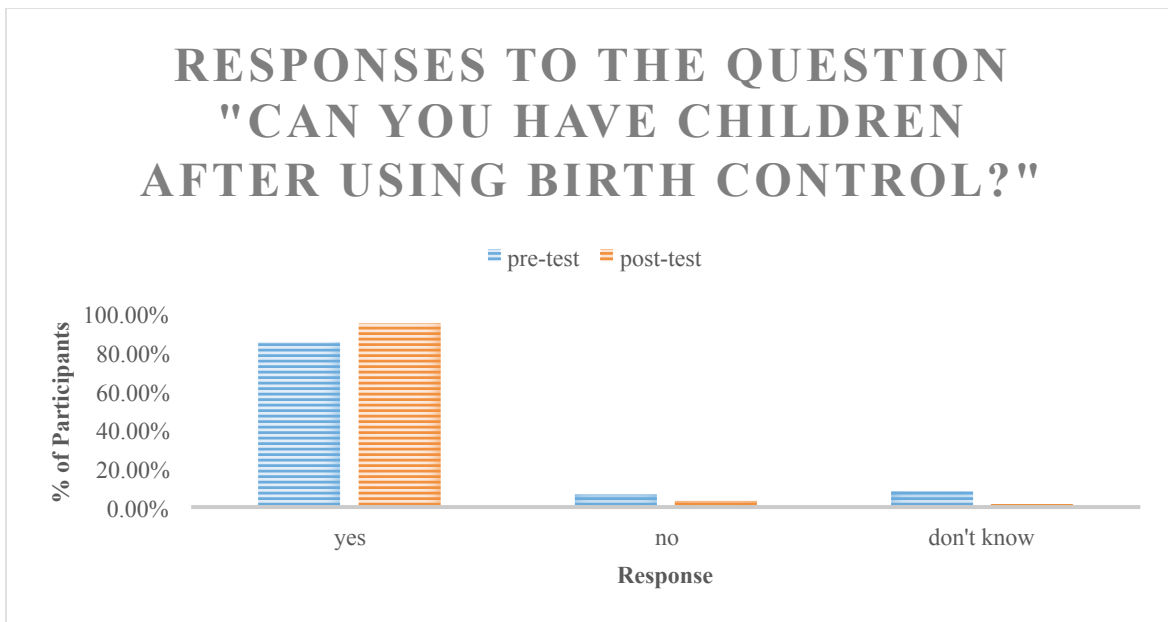


Figure 9. Responses to the question, “Can you have children after using birth control?” b percentage of participants.

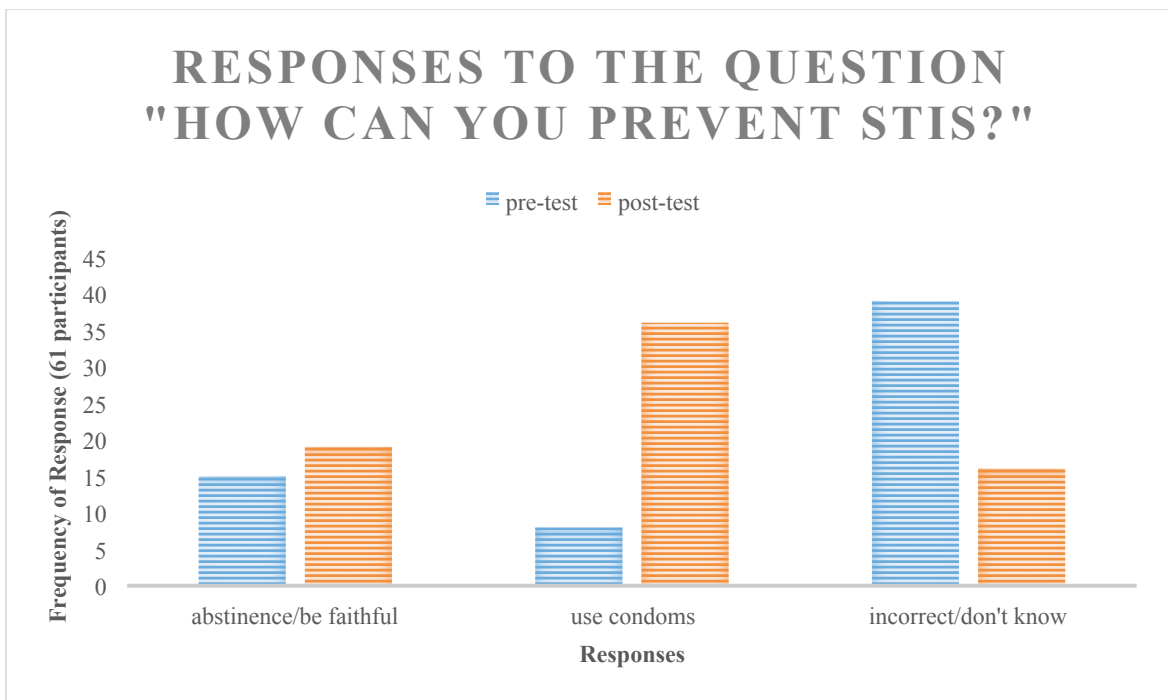


Figure 10. Response to the question, “How can you prevent sexually transmitted infections?” Two points were given for two possible responses: “use condoms” or “be faithful/abstinent.” Some participants provided both responses.

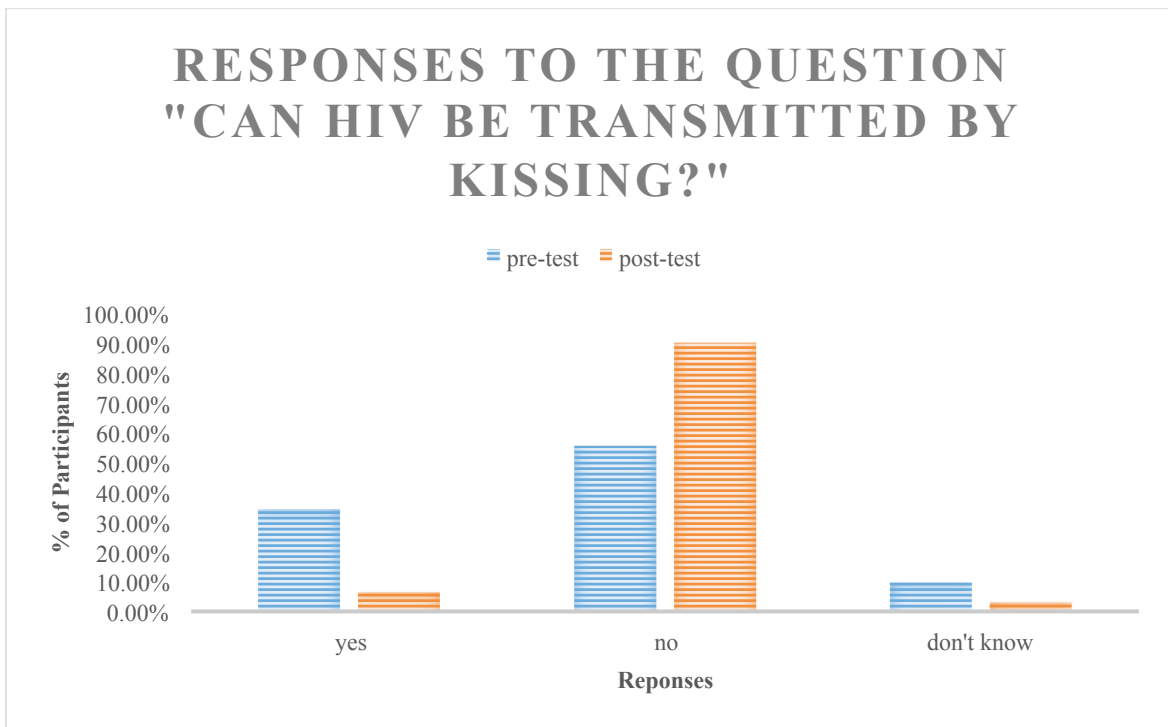


Figure 11. Response to the question, “Can HIV be transmitted by kissing?” by percentage of participants.



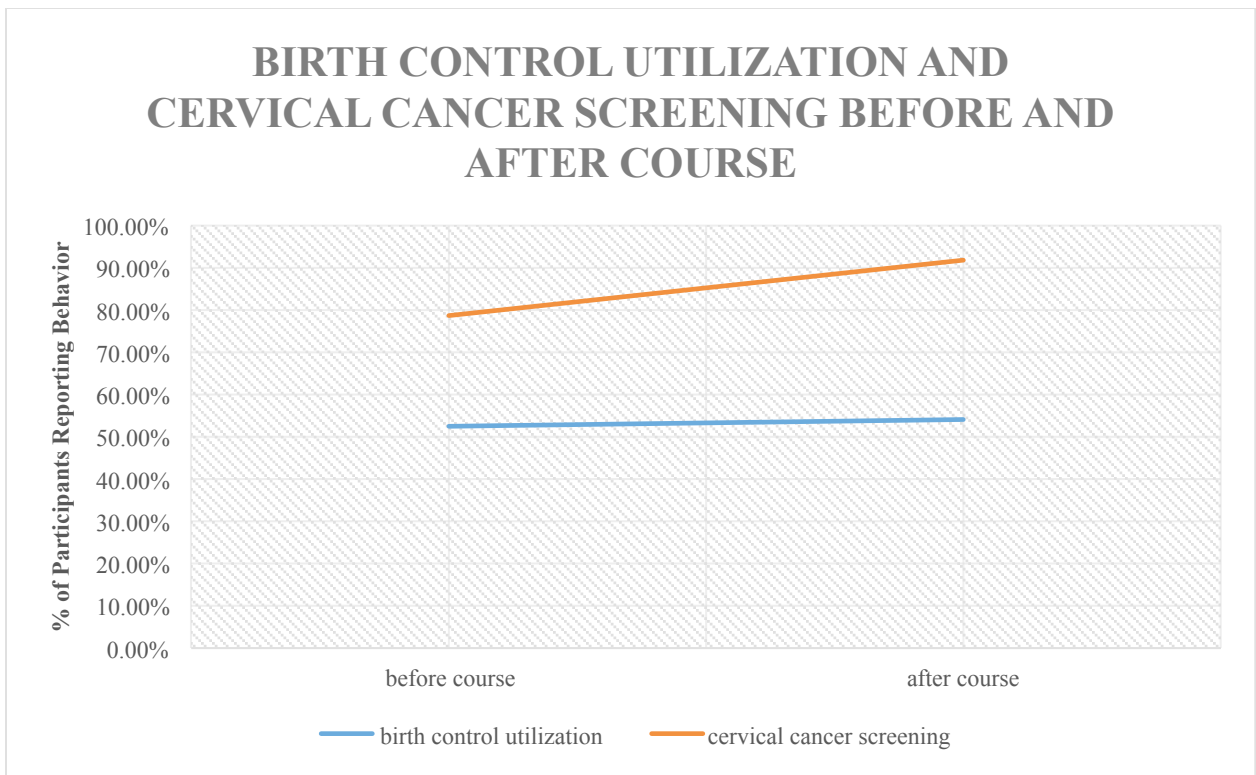


Figure 12. Birth control utilization and cervical cancer screening before and after the course. Shown by percentage of 61 participants who self-reported utilization of birth control or having had a pap smear (cervical cancer screening).

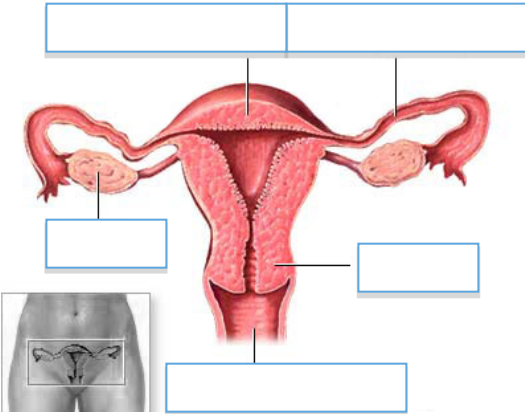
Appendix 1. Copy of knowledge assessment in Spanish.

**Nombre:**

**Edad:**

**Lugar:**

**Fecha:**

#	Pregunta	Respuesta
1	Cómo se llaman estas partes del cuerpo?	
2	Qué son 3 métodos de controlarse/planificación familiar que se usa en Guatemala?	1) _____ 2) _____ 3) _____
3	Para qué se hace el examen de Papanicolaou? (Para qué sirve?)	
4	Es normal si le baja sangrado vaginal unos años después de pasar por la menopausia?	a) Sí b) No
5	Es normal tener flujo claro?	a) Sí b) No
6	Podría decir 2 señales de una infección que se transmite por relaciones sexuales?	1) _____ 2) _____
#	Pregunta	Respuesta

7	Piensa usted que la planificación familiar (métodos para no tener hijos) causan cáncer?	a) Sí b) No  Marque lo que aplica: ___ T de cobre ___ Inyecciones ___ Pastillas ___ Otro: _____
8	Se puede tener familia después de controlarse de algún método?	a) Sí b) No
9	Qué se puede hacer para prevenir infecciones que se transmite por relaciones sexuales?	
10	Se puede transmitir el VIH por un beso?	a) Sí b) No

1. Alguna vez ha usado planificación familiar? Qué tipo de planificación? Está usando algún método ahora?

2. Alguna vez ha hecho Papanicolaou? Cuántas veces? Cuándo fue su última Papanicolaou?

